"The Long Goodbye"

Introduction

The aging population of the world is one of the most profound and universal changes affecting members of contemporary society. Between improvements in disease prevention, health promotion of the early twentieth century, and an increased interest in health and aging research, people are not only living longer than ever before in human history, but also in better health. In 1990, there were approximately 3 million people in the United States aged 85 and over, but by the year 2020 there will be 8 million elderly, and a projected 15-20 million by 2050 in the U.S alone (Finkel, 2000). This growth and change in the average life expectancy has, and will continue to have a disproportionate effect on the care of individuals, health care providers, and society as a whole while the number of elderly continue to exceed available resources. Greatly contributing to the stress/strain of resources are the chronic illnesses and disabilities that become most prominent in the later years, especially as people begin to live into their 80s and 90s. Mental disorders and symptoms are common among the elderly in primary care. A high proportion of residents are reported to suffer from mental disorders or clinical psychiatric symptoms. The most common disorder that affects approximately 20% of those 80 years and older, and 80% of elderly residents in specialized care is *Dementia* (Zarit & Zarit, 1998), often referred to as "the living death" (Innes, 2002).

Dementia illnesses are often the most feared and devastating disorders of later life. They are characterized by serious, often irreversible deterioration in cognition, that involve the progressive loss of every human function: reasoning, judgment, personality, emotional control, and eventually the ability to talk, dress, or speak. According to the Diagnostic and Statistical Manuel, IV edition (DSM IV), three main criteria needed for diagnosis of dementia are memory impairment, cognitive disturbance in at least one other area of functioning (e.g., aphasia, paraxial, agnosis, or a disturbance in executive functioning), and cognitive impairments severe enough to interfere with social or occupational functioning (Zarit & Zarit, 1998). The person with dementia suffers from one or a combination of two diseases: vascular dementia and/or Alzheimer's disease (AD). Alzheimer's disease, a progressive neurodegenerative disorder, affects about 60% of all elderly with dementia. (Belsky, 1999). AD results in the annual cost of care in the United States between $25,000 and $30,000, with a significant percentage due to behavioral and psychological symptoms of dementia (BPSD) (Finkel, 2000).

Alzheimer's disease, and dementia in general, are characterized by both cognitive and non-cognitive symptoms. There are several clinically distinct categories of non-cognitive symptoms refereed to as the Behavioral and Psychological Symptoms of Dementia, or BPSD (Ballard, Burns, Howard & O'Brian, 2001). BPSD have been defined as disturbances of perception, thought content, mood and behavior (Eryavec, Herrmann, Lanctot, Naranjo, & Reekum, 2002). Behavioral disturbances represent the foremost patient-management problem in nursing homes. Of the behavioral disturbances, aggression has been cited as the most common (18-65%) and principle management problem for staff management (Breier, Clark, Feldman, Juliar, Kadam, Mitan & Street, 2001).

Patients with dementia appear to display heightened tendencies towards aggression. According to Patel's description, aggressive behavior is an overt act, involving the delivery of noxious stimuli to, but not necessarily aimed at, another object, organism or self, which is clearly not accidental (Duursma, Eikelenboom, Haffmans, Jansen & Sival, 2002). Acts of aggression can be divided into multiple categories, the most prominent being physically aggressive and verbally aggressive behaviors. Physically aggressive behaviors include hitting, pushing, grabbing, kicking, etc., whereas verbally abusive screaming, cursing, and temper outbursts are classified as verbal aggression (Luxenberg, 2000). Verbal aggression is the most common and longest lasting form of aggressive behavior, whereas physical aggression is more prominent as the severity of dementia increases. Aggressive behavior has been found to be particularly common in frontal-temporal dementia (Luxenberg, 2000).

Aggression presents a significant problem in providing services for the elderly with dementia. It causes extreme stress for caregivers, in some cases provoking an aggressive response, and has been described as a primary predictor of caregiver burden (Deyn & Katz, 2000). Such a severe impact on the quality of life for both the patient and caregiver further complicates effective medical management. Demented patients who demonstrate acts of aggression also experience more stress and reduced quality of life in other domains. As it is often the last resort for many families who are no longer able to adequately provide care for their demented loved ones, the highest prevalence of agitation, aggression, and other behavioral disturbances are found in the nursing home. This shows aggression to be a primary predictor for initial institutionalization of demented patients. Once admitted, the patient may experience increased use of physical restraints and psychotropic medications such as anti-psychotics if they continue to display acts of aggression. This presents an increased risk of physical health problems such as weight loss, heightened frequency of falls, malnutrition, and can also lead to further cognitive decline in the elderly demented patients themselves. (Eryavec, Herrmann, Lanctot, Naranjo & Reekum, 2002). As of now, there are no cures for dementia or its behavioral disturbances. It may be most beneficial to examine the primary causes preceding aggressive behaviors to establish successful interventions and aid in the management of aggressive behaviors

Specific factors including cognitive impairment itself, as well as environmental characteristics within the nursing homes may increase the likelihood of, as well as facilitate the incidence of angry and aggressive acts towards staff, fellow residents, and the demented patients themselves. Cohen-Mansfield and Werner (1998) and Beck both found that cognitive impairment correlated with physical aggression. Several psychiatric symptoms, depression, hallucinations/delusions, and psychosis are believed to relate to physical aggression (Schreiner, 2001). This may be due to changes in brain chemistry, in particular, dysfunction of the serotonergic system that impairs an individuals judgment when irritable, and facilitates sudden anger, mistrustfulness, and paranoid ideation (Fairburn & Gedling, 1999). Residents may also be particularly sensitive to environmental disturbances, like those common in nursing homes during change of shift period. Type, frequency, and severity of aggressive behaviors have been reported to occur more frequently during "sun downing", evening and night hours (Burgio, Hardin, Hsu & Scilley, 2001). Behaviors such as hitting, pushing, and scratching coincided with bathing schedules, and aggression generally occurred more frequently during the intimate care of bathing, feeding, and dressing. (Schreiner, 2001). With increasing cognitive impairment, the demented individual may begin to misinterpret the environment. Language disorder is an under-recognized, yet very important problem for people with dementia living in care facilities. The inability to communicate basic physical needs such as hunger, pain, infection, and poor sensory perception, among other things, may lead to further cognitive deterioration, agitation and subsequent aggression. Other consequences include reduced participation in social activities, eventual social withdrawal, and an overall lowered quality of life that leads to an agitated individual's expression of aggression (Schreiner, 2001). In general, aggressive behavior may be an adaptive strategy in a situation were resources are so limited, that people who fight are more likely to get what they need (Belsky,1999).

While there is no cure for dementia, the best hope for minimizing the pain and burden for both nursing home residents and the care staff lies in studies, interventions, and services for both to make life as easy and fulfilling for the millions who cope with the difficulty of dementia on a daily basis.

Objective

The objective of my summer research is to examine the occurrence of both physical and verbal acts of aggression towards care staff, as well as between residents, of those diagnosed with mental disorders within multiple nursing home and psychiatric hospital environments. The above mentioned mental disorders will not be restricted to only dementia (Alzheimer's disease), but instead, also include disorders such as major depression and schizophrenia to enable a meaningful comparison across diagnostic conditions. It will be important to explore the context of formal care provision for people with dementia under the supervision of

care staff in the nursing home environment, as well as the relationships between unmet physical and psychological needs and the expression of anger and aggression in the elderly nursing home population with dementia. Other specific interests that deserve attention are the differences between AD patients who maintain similar levels of cognitive functioning, but overall different behavioral disturbance levels, and the changes in aggressive behavior throughout the course of dementia.

Additional research during fall, winter, and spring will look not only at staff interviews as the above mentioned, but may also include interviews with both patients and their family members to gain additional perspective on the occurrence of and reasons for aggression resulting from mental disorders within the elderly population.

Methods

My research will consist of both field sight observation-description as well as staff interviews with clinical managers and level of care staff, or "ward staff". The use of observation scales for aggressive behavior may provide insight into patient's aggressive patterns, as well as aid in the comparison of staff responses regarding aggressive behaviors. The behavioral and psychological symptoms identified in mental disorders such as dementia can also be identified clinically, both by direct observation and by caregiver/patient interviews. At least three nursing homes and psychiatric hospital facilities within Los Angeles and Orange County, CA will serve as representative research sites. A few possible sites include Ocean View Community, Sunbridge Country, Villa Westwood, and Good Shepard located in Los Angeles and Santa Monica. Due to the limited time available of most care staff and clinical managers, financial compensation may be offered in correlation to the subject's hourly wage, or a set fee of approximately $25 per interview. All staff and patients within the facilities who participate will be assured of privacy and confidentiality, with the option to view any written results upon completion. I will also speak with the ethics board of each location to approve the study, and obtain written consent. Patients who express behavioral and psychological symptoms of dementia, and meet DSM IV criteria for the diagnosis of dementia, will be the subjects of observation within the facilities. Patients who express behavioral and psychological symptoms of dementia and meet DSM IV criteria for the diagnosis of dementia will be the subjects of observation within the facilities. If possible, it would be beneficial to look into the patient's medical history, family history of mental disorders, personal psychiatric history, duration of dementing illness, education level, previous care-receiving arrangement, and current drug regimen. Once all of the data is collected, I will begin to analyze and formulate additional topics of interest necessitating future research.

Personal Statement

As people in our society live longer and in better overall health, it is a sad fact of life that so many of us will have to experience the pain, confusion, and stress of seeing or taking care of the elderly loved ones in our families. Unfortunately, I have already witnessed two such life-altering tragedies within my family, and experienced the difficulty in caring for a loved one diagnosed with Alzheimer's disease type dementia.

Having been raised by a single, working mother, I was fortunate enough to be looked after by grandparents who resided just 3 floors above my apartment in the same building. We ate dinner together on a nightly basis, and were a close-knit family unit unlike many I observed in other families. It was a rude and unexpected awakening when my grandmother experienced a series of acute brain strokes in 1992, and was later diagnosed with Alzheimer's disease. Gradually, her short-term memory began to deteriorate, my mother's and my names began to seem almost interchangeable, her once beautiful and warming gestures became erratic movements, and eventually she began to expressive aggressive tendencies towards by grandfather and strangers. After a long seven-year struggle of aiding my grandmother with activities of daily living, and her later admittance into a special Alzheimer's unit within a nursing home facility, she passed away due to complications of pneumonia. My grandfather has recently began to show symptoms of dementia, with complications due to Parkinson's

disease, the presence of delusions, and persistent extreme depressive symptoms. Unable to care for himself, he is currently being considered for admission into several Santa Monica area nursing centers.

These experiences have had a profound affect on my interest in, knowledge of, and desire to research multiple features of disease and aging in last resort nursing home and psychiatric facilities. I am particularly interested in questions revolving around what may be done in the future to aid both elderly individuals diagnosed with various mental disorders to live more fulfilling lives, as well as their families. I feel that research experience now will aid in my future academic career, later life profession of working in geriatrics with Alzheimer's patients and their families, and have very personally rewarding effects in my personal life.

Timeline

Spring 2004:

-Conduct thorough research of available literature and academic journal articles (e.g., Int. J Geriatric Psychiatry, J Applied Gerontology, J of America Geriatric Society, Int. J of Mental Health, Clinical Gerontologist, J Psychopharmacology, American J of Public Health, J Psychosocial Nursing, etc).

-Begin to contact potential nursing home facilities, clinical managers and care staff for interviews and potential nursing home residents for field site observations.

-Start initial independent research under the guidance of Professor Novaco.

-Completion of a project report as an academic research manuscript, with the ultimate goal of submission to a scientific journal.

-Volunteer at an Orange County long-term nursing home residency to gain first hand knowledge of the environment, residents, and staff, as well as create a strong foundation for later research.

Summer:

July:

-Finalize choice of observation and interview sites within Los Angeles and Orange County and begin to conduct staff interviews and field site observations.

-Continue to research literature and journals.

-Offer volunteer assistance at an additional 3-5 long-term nursing home facilities.

-Enroll in Social Ecology 199 independent research under the guidance of Professor Novaco.

August/September:

-Complete staff interviews and continue resident observations

-Finish reading all literature and begin to arrange.

-Analyze gathered data from tape recordings and notes, and organize observational material into concrete findings.

-Begin writing data analysis.

-Continue enrollment in SocEcology 199 independent research with Professor Novaco.

Fall:

-Begin to write honors thesis examining the relationship between dementia/Alzheimer's disease (AD) and aggression within the elderly population that resides in both long-term nursing care facilities and psychiatric hospitals, and such implications for future generations.

-Continue work as a volunteer in both previous and new nursing home environments, and short term care hospital units as well.

-Work on research paper to be submitted to UCI Undergraduate Research Journal for possible publication, and work on additional journal publications.

-Prepare presentation for spring UROP Symposium.

Winter:

-Quarter leave of absence to work on thesis, and volunteer at nursing home facilities in Rio de Janeiro, Brazil.

Spring:

-Present research at the UCI Undergraduate Research Symposium in May, 2005.

-Submit paper for publication to UCI Undergraduate Research Journal, as well as additional publishing journals.

Questions for interview subjects

For Caregivers:

-Ask for specific caregiver characteristics.

-What are daily routines? Weekly? What tasks are regular but unscheduled?

-Do you believe that those demented patients w/AD/Dementia are aware of your interactions or what you do to/for them?

-Do they still seem to maintain a self-identity?

-Do you believe that they are aware of you presence and role of caring for them, or of who they are themselves?

-What are the demographics of those who commit the most aggressive acts?

-Are males or females more likely to or most often display acts of either physical or verbal aggression?

-What is the prevalence of mental disorders among elderly patients in primary care?

-What are the person's symptoms?

-How has the patient been diagnosed…with Dementia or Alzheimer's? What criteria was used for diagnosis? Who diagnosed?

-Have underlying medical disorders (delirium) been ruled out or treated?

-Have neuropsychiatry syndromes related to dementia (psychosis, depression, anxiety) been properly identified and treated with recommended medication?

-What are the frequency and severity of each behavior (hitting, kicking, biting, scratching, yelling, etc.) in the previous 2 weeks? What were the conditions of aggressive acts (during intimate care--being washed, dressed or fed, suddenly or unexpectedly w/out any obvious reasons, because the subject was impatient, any other reason)?

-To what extent do the resident's display resistant behavior during the performance of personal care (bathing, dressing, eating, toileting)?

-What were the behaviors likely to be caused by (hallucinations, delusions, delusions)?

-What is/are the most common aggressive behaviors observed?

-Did the aggressive behavior appear to be directed to one or more specific people?

-What stressed caused the problem behaviors to irrupt?

-How long has the difficulty been going on?

-Do acts/signs of aggression (physical and verbal) get progressively worse as the individuals cognitive impairment progresses (cognitive ability declines/deteriorates)?

-Do dementia/AD patients display significantly more acts of aggression/violence then non-demented residents?

-Is medication being taken, and if so, as prescribed? What type of medications are they on?

-Are medication side effects or drug interactions causing problems?

-Have environmental stressors been evaluated and altered?

-How would you describe the verbal communication skills of the residents?

-Do you feel that there are often misinterpretations due to language difficulties between you and the residents?

What seems to lead to or be the reasons for the social withdrawal of specific residents?

-Do you believe that prior training has been beneficial for the interactions between you and the residents?

-What spaces/space relationships (environmental setup) are effective in every day functioning, as well as lowering acts of aggression (physical and verbal)? Which ones are ineffective?

-Under ideal circumstances, what environmental conditions, relationships, or equipment/furnishings would you choose to aid in your job?

-Do you feel adequately informed and supported in your job?

-Is there family counseling available to aid in the adjustment for both family and residents?

For management

-What is the philosophy of care in the facility?

-What are the programs/activities/levels of care offered within the facility?

-What additional programs/services should be offered or feel would be beneficial given ideal circumstances (funding, staff support, sufficient number of caregivers)?

-What spaces/relationships work well for current programs and activities?

-What is the staff turnover rate in the nursing home/dementia special care unit?

-What do you see for your facility/programs in the future?

-What is the level of your staff's involvement with residents?

-What tasks are required by Federal or state agencies? What activities are performed as a result of the facilities' programs?

Questions to research myself

-What is the frequency of aggressive, physical and verbal acts?

-What are the underlying pathogenic mechanisms?

-Is the aggression related to neurobiology, or to social and personality factors?

-Is the physical environment safe?

-Is an appropriate level of stimulation, social interaction, and activity provided?

-Are available staff levels and skills mixed appropriately to the patient?

-Does the building help patients to find their way around?

-Is the quality of verbal and non-verbal communication appropriate?

-Is the patient treated with dignity and respect?

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